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COGKNOW: Development of an ICT Device to Support People with Dementia

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ABSTRACT

Objective: To develop a successful user-validated cognitive prosthetic device with associated services to help persons with mild dementia.

Setting: The ICT solution will be developed by a consortium of eleven institutes in eight countries in Europe. It will be tested and evaluated by users (persons with dementia and their carers) in 3 European cities – Amsterdam, Belfast and Luleå.

Methods: To identify and analyse the needs of persons with dementia, workshops and interviews were conducted with Alzheimer patients suffering from mild dementia, and their carers in three European cities. A literature search was also performed to identify existing proven effective ICT solutions for persons with dementia.

Results: The most important needs and the most preferred ICT solutions identified by participants were (i) Activity reminders e.g. for eating meals; (ii) Item locators; (iii) Picture dialling to keep in contact with family and friends; (iv) Support for pleasure activities; (v) Enhancement of feelings of safety.

Conclusion: Based on the needs identified, a prototype solution will be built, tested and modified as an iterative process. The device will ultimately be evaluated to see if it can enhance feelings of autonomy and quality of life of persons with dementia.

INTRODUCTION

Dementia is a progressive decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal ageing. Persons with dementia usually have a combination of symptoms involving impairments of memory,

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speech, thought, perception and reasoning. This can result in the inability to perform complex tasks such as preparing a meal, or even basic functional activities such as washing and eating. Often there are changes in personality, behaviour and psychological functioning, such as apathy and aggression^{1,2}.

Dementia is associated with increased age. The estimated prevalence is 5-10% in the over-65s, 20% in the over-80s and 45% in those aged 95 or older^{3,4}. The most prevalent type of dementia is Alzheimer's disease (AD). Two thirds of older people and one-third of younger patients (50–65 years old) with dementia have AD.

With global life expectancy rising, the prevalence of dementia is also expected to rise and this has a significant economic impact in Western countries. Taking into consideration the associated costs of community-based caring strategies and the emotional and economic burdens associated with institutionalisation, coping with dementia is best considered in the context of healthcare strategies, as well as social and economic policies.

Until recently strategies and policies were based predominantly on what other persons considered important for persons with dementia. Relatively few studies have been conducted in which persons with dementia have been surveyed to focus on their specific unmet needs.

Quality of life is an important aspect for all patients. A recent report examining quality of life issues of dementia sufferers identified seven key domains⁵:

- Physical and mental health
- Social contact with family and friends
- Being useful to others
- Enjoyment of activities
- Self-esteem (being respected by others)
- Self-determination
- Freedom

COGKNOW is a European Commission supported project that aims to identify the needs and potential solutions for people with dementia, and particularly those with mild dementia⁶. The project commenced in September 2006 and is expected to last three years. Its main objective is to provide a portable, remotely-configurable, user-validated cognitive prosthetic device, to assist people with mild dementia navigate through their day. It aims to do this by providing cognitive reinforcement to dementia sufferers for the following four areas:

- Help them remember things
- Maintain social contact
- Perform daily living activities
- Enhance their feelings of safety

The project involves eleven participating organisations in eight countries. In three iterative cycles of one year each, the needs of persons with dementia will be analysed, possible ICT solutions will be identified, and their functional requirements will be formulated. Then a prototype of the cognitive prosthetic device and associ-

ated support services will be developed and evaluated. This paper deals with the first phase, i.e. performing a needs assessment analysis to develop the first prototype.

METHODS

To analyse the needs of persons with dementia, workshops and interviews with persons suffering from dementia and their carers were conducted in three cities – Amsterdam (The Netherlands), Belfast (Northern Ireland) and Luleå (Sweden). Selection of patients was confined to those suffering from Alzheimer's disease and with mild to moderately severe cognitive decline. Patients were chosen from clinics or from meeting centres for patients with dementia at the different test sites. The diagnosis and assessment of patients was performed by a clinician at the clinic (neurologist/psychiatrist/geriatrician) and a programme coordinator at the meeting centres. The diagnosis of Alzheimer's dementia was based on the criteria specified in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR)⁷. Cognitive decline assessment was performed using the Global Deterioration Scale proposed by Reisberg and colleagues⁸ (Table 1).

In each city, a maximum of six people with dementia and their carers were chosen to participate in workshops and interviews.

Table 1. *Global Deterioration Scale for cognitive assessment*

Stage 1	No Cognitive Decline	Experiences no problems in daily living
Stage 2	Very Mild Cognitive Decline	Forgets names and locations of objects May have trouble finding words
Stage 3	Mild Cognitive Decline	Has difficulty traveling to new locations. Has difficulty handling problems at work
Stage 4	Moderate Cognitive Decline	Has difficulty with complex tasks (finances, shopping, planning dinner for guests)
Stage 5	Moderately Severe Cognitive Decline	Needs help to choose clothing Needs prompting to bathe
Stage 6	Severe Cognitive Decline	Needs help putting on clothing. Requires assistance bathing; may have a fear of bathing. Has decreased ability to use the toilet or is incontinent
Stage 7	Very Severe Cognitive Decline	Vocabulary becomes limited, eventually declining to single words. Loses ability to walk and sit. Becomes unable to smile.

Patients interviewed for the study had mild to moderately severe cognitive decline (Stages 3–5).

Workshops on User Needs

Individual workshops were carried out involving the dementia patients, their informal carers and their professional carers. Each workshop was attended by at least two members of the project team –one to lead the discussions and the other to play a supporting role including taking notes and making observations. The workshops were conducted following a set format, and a list with explanations of the four COGKNOW areas was prepared and put up beforehand. The workshops started with an explanation of the project, the aims and structure of the workshop, and an introduction of all the participants. They focused on discussing the needs, wants and demands⁹ of patients in the four COGKNOW areas related to improving their Quality of Life (QOL) and autonomy. To assist in this process we conceptualised and verbalised a patient's day from the time they awoke in the morning to the time they went to sleep at night. To focus on different time frames during the day, time-specific pictures were shown in a slide show and possible ICT solutions for the needs, wants and demands of patients were discussed. For each COGKNOW area some potential solutions were also shown in the slide show. In-depth discussions were carried out with the participants, to explore various possible directions of solutions, and the priority of preference for possible solutions for different persons with dementia.

Interviews

When participants were unable or did not want to join the workshop, interviews were conducted following the same structure as in the workshops. Furthermore, in separate interviews with all persons with dementia and their carers, background characteristics were documented (age, education, relation, patient, carer, etc.), as well as cognitive disabilities. These encompassed:

- The cognitive section of the Cambridge Examination for Mental Disorders of the Elderly CAMDEX¹⁰
- Difficulties performing activities of daily living¹¹
- Needs¹²
- Experienced autonomy¹³
- Coping^{14,15}
- Informal network¹⁶
- Quality of life¹⁷

Information obtained from the interviews was used to specify the technical requirements of the device to be developed. All activities focused on the development of a really user-friendly application, as it is perceived that this is a strong and currently unmet requirement for persons with dementia.

Literature Search

A literature search was also performed to identify existing proven effective ICT solutions for persons with dementia, healthcare models and technological infrastruc-

tures. This information was used to contribute to the formulation of the functional requirements of the prototype to be developed and tested in the three countries.

RESULTS OF THE WORKSHOPS ON USER NEEDS AND POSSIBLE ICT SOLUTIONS

The data on user needs and ICT solutions was collected in Amsterdam by means of workshops and one individual interview, in Belfast by means of individual interviews and in Luleå by means of individual interviews and group interviews. In Amsterdam, all participants were willing to participate in the workshop, but one couple was on holiday at the time of the workshop. They were therefore interviewed subsequently in separate interviews for the dementia patient and the carer. In both Belfast and Luleå, persons with dementia and their carers were not comfortable talking about their illness and needs in workshops. Consequently they participated in small group interviews. The characteristics of the participants at the three test-sites are shown in Table 2.

The most important needs and the most preferred ICT solutions for each COG-KNOW area were identified by the participants (Table 3). These were combined to create a list of the top preferred ICT solutions and included:

- Activity reminders e.g. for taking medications
- Item locators
- Picture dialling to keep in contact with family and friends
- Support for pleasure activities

Table 2. *Characteristics of the participants at the three test-sites*

	Amsterdam (n=6)	Belfast (n=6)	Luleå (n=5)
Persons with dementia			
Age	Mean 64.0 (range 56–78)	Mean 72.7 (range 65–86)	Mean 67.8 (range 60–77)
Gender	3 female 3 male	5 female 1 male	3 female 2 male
Civil status	5 married 1 divorced	3 married 2 widowed 1 single	5 married
Carers			
Age	Mean 58.5 (range 49–78)	Mean 53.0 (range 40–72)	Mean 61.4 (range 23–78)
Gender	4 female 2 male	3 female 3 male	2 female 3 male
Relation to patient	5 spouses 1 daughter	3 spouses 2 children 1 cousin	4 spouses 1 son

Table 3. List of preferred ICT-solutions identified at the three test-sites

Amsterdam	Belfast	Luleå
COGKNOW area: Support for memory Reminding and remembering		
Reminder for not forgetting activities/appointments/take medicine/to take things outdoors, like key and mobile phone/mobile device. The solution should preferably be stationary with touch screen as well as mobile	Item locator, misplacement of items is a key early, and almost universal, symptom of a dementing illness – reflected in BCH workshops and literature review (see SMART home, BIME (Bath Institute of Medical Engineering))	Activity reminder/electronic calendar, stationary device with touch screen
COGKNOW area: Support for social contacts Enable communication with family and friends		
Picture dialling function on touch screen integrated within the screen of the stationary device of the reminding system (thus not as a separate pictophone)	Electronic calendar with emphasis on appointments and social activities pending. Usefulness emphasised in workshops and within research community; see Forget-me-not http://www.ihagen.no/english.htm	Picture dialling function on touch screen integrated within the screen of the stationary device of the reminding system (thus not as a separate pictophone)
COGKNOW area: Support with daily activities Help executing activities that provide pleasure, recreational activities, useful activities		
Support for activities for pleasure: e.g. picture gramophone ENABLE-project integrated within touch screen of activity reminder or picture of TV on touch screen that starts the TV when touched	Pill dispenser – medication management issue identified as an important “daily activity” particularly within workshops and concerning elderly persons generally	Support for activities for pleasure: e.g. picture of TV on touch screen of the stationary device of the activity reminder that starts the TV when touched
COGKNOW area: Enhance feelings of safety Prevent people with dementia from experiencing anxious or dangerous situations		
Support during cooking e.g. Cooker usage monitor Signal on stationary and mobile activity reminder device. or Warning to close door/take things outdoors such as keys or simple mobile phone with or without GPS	Picture telephone identified in workshop discussions and see Mobile Telecoach	Reminder to turn devices of on stationary device, for example the stove (not as a separate artefact, but as a function within the activity reminder system) or Direct or easy contact possibilities to a service or emergency line (not as a separate artefact, but as a function within the reminder system)

attention. Martin touches the picture to acknowledge the reminder and goes to the kitchen to prepare his lunch.

Picture Dialling

Martin would like to speak to his son and daughter frequently, but has difficulty remembering their numbers or locating them in a list of stored numbers. To call his daughter, Martin touches the phone symbol on the COGKNOW Day navigator (Figure 2). This opens a phone book with photographs of close relatives and friends. Martin touches the photo of his daughter and the COGKNOW Day navigator makes a telephone connection to his daughter so that he can talk to her.

Support for Pleasure Activities

In the morning Martin likes to listen to the radio. He had difficulty using his old radio because it had a lot of small buttons. He now uses the COGKNOW Day navigator to turn on the radio (Figure 2). When he touches a radio pictogramme on the screen, the radio is switched on to his favourite station which is preconfigured in the system.

Safety Warning

When Martin has left the front door open, the door sensors provide a signal to the COGKNOW Day navigator and an alarm is given together with a written message

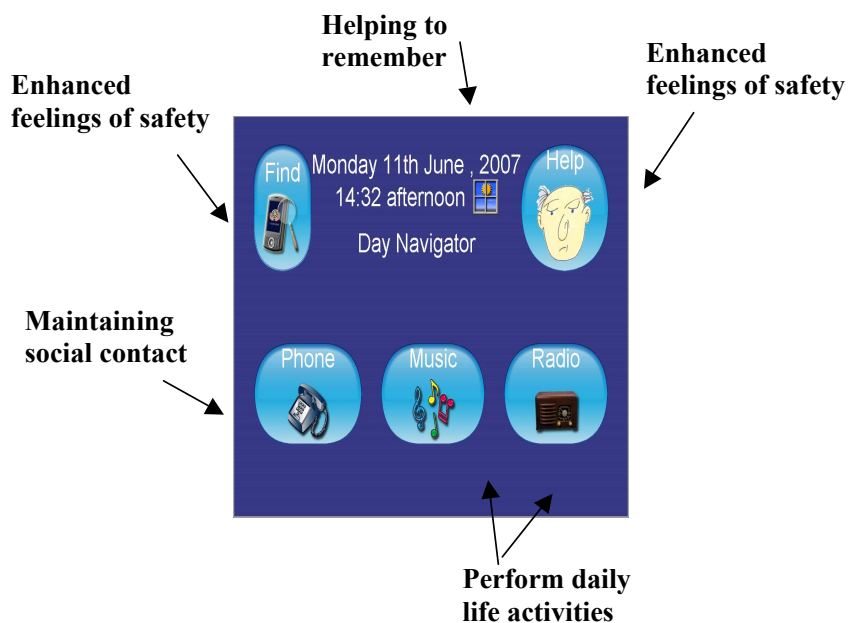


Figure 2. Screenshot of the COGKNOW Day Navigator interface showing the various functionalities for supporting dementia patients

and picture of an open door. Only when Martin closes the door does the alarm stop.

DISCUSSION

Effectively supporting people with dementia is a great challenge. An increasingly ageing population has resulted in long waiting lists for institutional accommodation such as sheltered housing, homes for the elderly and nursing homes. Consequently the majority of people with dementia will have to 'survive' in their own homes, but fortunately many elderly people do in fact wish to stay in their own homes for as long as possible. Although this relieves the pressure on nursing homes and other institutional care facilities, it generates great pressure on informal carer(s), such as spouses, children, other family members and friends. This pressure is exacerbated by an increasing shortage of professional community carers.

Studies in which people with dementia themselves describe their needs indicate that the most frequently identified unmet needs are in the areas of information (on treatment, care and support, appointments), memory problems, communication, meaningful activities during daytime, and psychological distress^{18–23}. The COGKNOW project aims to support elderly people with mild dementia by focusing on their real needs and wants. The solution will help this group of people to navigate through their day and improve their independence and quality of life. In the initial part of the project we have conducted interviews to identify the needs and requirements of patients with dementia in order to construct a cognitive ICT device and associated support services. Based on our findings a first prototype has been developed in collaboration with all the COGKNOW partners, and will be evaluated in field tests at the same sites where the interviews were conducted, i.e. Amsterdam, Belfast and Luleå. Testing will be an iterative process with dementia patients and/or their carers provided with the COGKNOW device to use on a daily basis for a period ranging from several days to several weeks. During testing of the device, data will be collected by means of standardised scales and questionnaires, and semi-structured interviews. Evaluation will focus on human factors, e.g. user friendliness and usability of the device, technology factors, e.g. device reliability, system stability, and business factors required for success. Ultimately evaluation will seek to determine the ability of the prototype to enhance (actual and perceived) autonomy and quality of life of persons with dementia, and in particular with respect to the four areas targeted by COGKNOW - remembering, maintaining social contacts, performing daily life activities and enhancing feelings of safety.

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